

VIEWPOINTS



A quarterly newsletter for the
Parkinson's Community of British Columbia



FALL
2016

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Dr. Ahlskog discusses the nuts and bolts of Parkinson's disease



Dr. J. Eric Ahlskog, PhD, MD, is a Professor of Neurology at the Mayo Medical School and has been Chair of the Mayo Section of Movement Disorders at the Mayo

Clinic in Rochester, Minnesota. He is the author of *The New Parkinson's Disease Treatment Book* and has over thirty years of experience treating people with Parkinson's disease (PD). He is widely considered to be a leading expert on PD. In June 2016, Parkinson Society British Columbia (PSBC) invited him to speak at the Annual General Meeting, as well as present at community talks in Abbotsford and Victoria.

▶ Dr. Ahlskog's presentation at PSBC's AGM is now available online – visit <http://bit.ly/DrAhlskog> to view.

What are your thoughts on the theory that Parkinson's disease has a long pre-clinical period?

Evidence supports a long pre-clinical period, especially based upon the work of Professor Heiko Braak, the German neuroanatomist who has developed a staging scheme for PD. He proposes that the motor symptoms of PD (e.g., tremor, slowness, stiffness, walking problems) reflect progression to middle stages of the PD process. Rapid eye movement (REM) sleep behavior disruption, loss of sense of smell, constipation or depression/anxiety tends to develop earlier in the Lewy disease process, often prior to the motor symptoms. For example, constipation or REM sleep disturbances may precede PD motor symptoms by 20 years or more. The disease itself progresses slowly and incompletely over a long period of time (Ahlskog, 2016).

What is the significance of dopamine and Lewy bodies in PD?

The brain is analogous to an enormous computer, controlling our actions, thoughts and emotions. Chemical messengers called neurotransmitters transmit signals from one brain cell (neuron) to the next. Dopamine is the substantia nigra neurotransmitter that transmits signals to the striatum. This brain circuit modulates movement, posture and influences mood (Neurotransmitters, n.d.). People with Parkinson's have very low levels of brain dopamine. Years ago, it was discovered that replenishment of dopamine effectively treats Parkinson's symptoms.

In 1913, Dr. Frederick Lewy reported unique changes in the brains of people with PD. Under the microscope, he found small deposits of a proteinaceous (protein) material in certain brain areas of deceased people who had PD. These deposits ("Lewy bodies") are considered the microscopic marker of PD.

After many years living with PD, some people develop medicine-refractory motor symptoms, cognitive impairment and autonomic symptoms (e.g., urinary, low blood pressure). Notably, these are not caused by low dopamine levels and hence do not benefit from dopamine replacement measures. In other words, this reflects proliferation of the Lewy body neurodegenerative process to non-dopamine brain regions. This has implications for future research directed at finding the "cure" for PD; research directed at dopamine restoration will not provide the cure. Rather, we need to understand the mechanisms of this Lewy neurodegenerative process, which would be a crucial step toward the "cure" (Ahlskog, 2016).

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DR. AHLKOG DISCUSSES THE NUTS AND BOLTS OF PARKINSON'S DISEASE

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? *Are there any drugs that slow the progression of Parkinson's disease?*

There is no proof of a neuroprotective effect from any drug. While there are no drugs that have been proven to slow the symptoms of Parkinson's, there is a substantial volume of scientific literature that convincingly argues for exercise as a means of slowing the progression of Parkinson's. Specifically, this relates to ongoing aerobic exercise (Ahlskog, 2016).

? *Why is exercise beneficial?*

Studies on animals have documented that exercise enhances neuroplasticity. Neuroplasticity implies the generation of new neural connections or brain pathways. Animal studies have also documented exercise-related generation of neurotrophic factors in the brain; such factors are comparable to putting fertilizer on your lawn. Several studies involving humans have documented that midlife exercise significantly reduces the later risk of not only PD, but also dementia and mild cognitive impairment. There are a number of studies that have reported an association between fitness and long term cognitive function and integrity (Ahlskog, 2015, p. 121).

? *What type of exercise do you recommend?*

Any type of regular aerobic exercise should be beneficial for people with Parkinson's. This might include going for brisk walks, playing racquetball, tennis, using the gym, PWR! training – anything that makes you hot, sweaty and tired. The amount of



exercise that captures the full benefit has not yet been established. I recommend an hour of aerobic exercise every other day, or one hour four times a week (Ahlskog, 2016).

? *When do you recommend an individual with Parkinson's start managing their symptoms with medication?*

A Parkinson's diagnosis does not necessarily mean you should immediately start a medication. Since there are no drugs proven to slow disease progression, the only reason to take a medication is to manage symptoms. If the symptoms do not bother you, you may wait until they do. The goals of medical treatment are twofold:

1. Optimize quality of life;
2. Control the motor symptoms sufficiently to allow regular exercise (Ahlskog, 2015).

? *What drug(s) do you suggest to individuals who may want to manage their symptoms medically for the first time?*

Carbidopa/levodopa is the gold standard medical treatment for Parkinson's disease. Levodopa, the active component of carbidopa/levodopa is naturally produced by our bodies – it is from a class of natural substances called amino acids, and levodopa is the immediate precursor of dopamine. The other primary drugs used to treat PD also work through dopamine but are much less efficacious and some have substantially more side effects.

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I recommend using the regular (immediate-release) formulation of carbidopa/levodopa instead of the sustained-release formulation, since this provides more consistent and predictable responses. It should be taken on an empty stomach, at least an hour or more before a meal or at least 2 hours after the end of a meal. I start patients on one 25/100 carbidopa/levodopa tablet, three times a day. The most I prescribe is three of the 25/100 carbidopa/levodopa tablets each dose. In the initial few years, three doses daily are appropriate; however, later, more doses per day may be necessary.

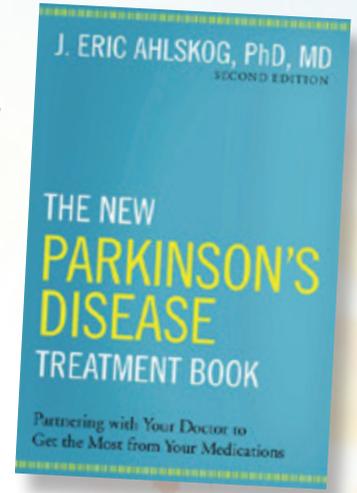
Carbidopa/levodopa has a few important side effects. It can lower your standing blood pressure, translating into faintness when upright. If each levodopa dose is more than you need, involuntary movements may be provoked (dyskinesias), which resolve if each dose is lowered. Carbidopa/levodopa can also cause nausea but does not induce stomach ulcers (the nausea is mediated via the brain nausea centre).

Do dopamine agonists cause unusual side effects and, if so, why?

The two oral dopamine agonists used for Parkinson's disease have a specific affinity for the D3 dopamine receptor class. These D3 receptors are predominantly found in the brain's limbic system, which plays a role in the experience of reward. Chronic treatment with these dopamine agonists may provoke pathological behaviours, such as compulsive gambling, sexual indiscretions, excessive spending, etc.; these pathologic behaviours have been documented in

about a quarter of PD patients taking therapeutic doses of pramipexole or ropinirole. These dopamine agonists may also trigger hallucinations, delusions, drowsiness or swelling (Ahlskog, 2016).

Dr. Ahlskog's first and second editions of *The Parkinson's Disease Treatment Book: Partnering with Your Doctor to Get the Most from Your Medications* (2005) and (2015) are available to members of PSBC, and can be borrowed from the Society's library.



▶ For more information on other library resources, please visit: www.parkinson.bc.ca/resources-services/library or contact Myriame Lépine Lyons, Education & Support Services Coordinator at mlepinelyons@parkinson.bc.ca or 1 800 668 3330

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Do you have Parkinson's related legal issues?



Through a partnership with PSBC, the law firm of **Blake, Cassels & Graydon LLP** offers free of charge legal services to people with Parkinson's in British Columbia.

The Litigation Support Program from Blakes addresses legal issues such as discrimination against individuals with Parkinson's in the workplace; discrimination in accommodations, services or facilities that are generally available to the public; and, wrongful denial of disability insurance or denial of government services.

If you have a legal problem relating to Parkinson's disease, please contact **Jean Blake, CEO** at jblake@parkinson.bc.ca for more information.

ask an expert

Joanne Taylor answers your questions on personal planning



Joanne Taylor is the Executive Director of the Nidus Personal Planning Resource Centre, a non-government, charitable organization that assists the public with personal planning. She is also the Registrar of the online Personal Planning Registry, a centralized repository for personal planning documents. Joanne credits much of her practical expertise on personal planning to her father, John Taylor, who had Parkinson's disease (PD).

? **What is personal planning?**

Personal planning refers to the formal, legal arrangements you make in case you need assistance during your lifetime due to an illness, injury or disability.

Personal planning involves four aspects of your life: health, personal, legal and financial. It addresses issues that arise when you are alive, whereas estate planning deals with matters that arise after your death, such as settling your estate.

You may have heard about 'advance care planning.' This term is typically used by the health care system, and applies to the health care aspect of personal planning.

? **When should an individual begin to plan?**

It is never too early to plan. Shortly after his PD diagnosis in 2004, my father made a Representation Agreement Section 9 (RA9) through Nidus. A couple of years later, he revoked (cancelled) earlier versions of both his will and his Enduring Power of Attorney and made new documents to better reflect his wishes and values. His actions reminded me to

update my own personal planning and estate planning documents.

? **What are the benefits of planning in advance?**

I can personally attest that personal planning can save time and help ease the burden of already challenging situations. For example, since I was named in my father's RA9 (a representation agreement), I was able to help him communicate with UBC Movement Disorder Parkinson's Clinic staff. This became particularly important as his speaking voice became quieter and more difficult to understand.

Again, personal planning does not only apply to health care. Since I was named in my father's Enduring Power of Attorney (EPA), I was able to use this document in 2012 to take care of my father's finances at the bank, as well as redirect his mail when he moved.

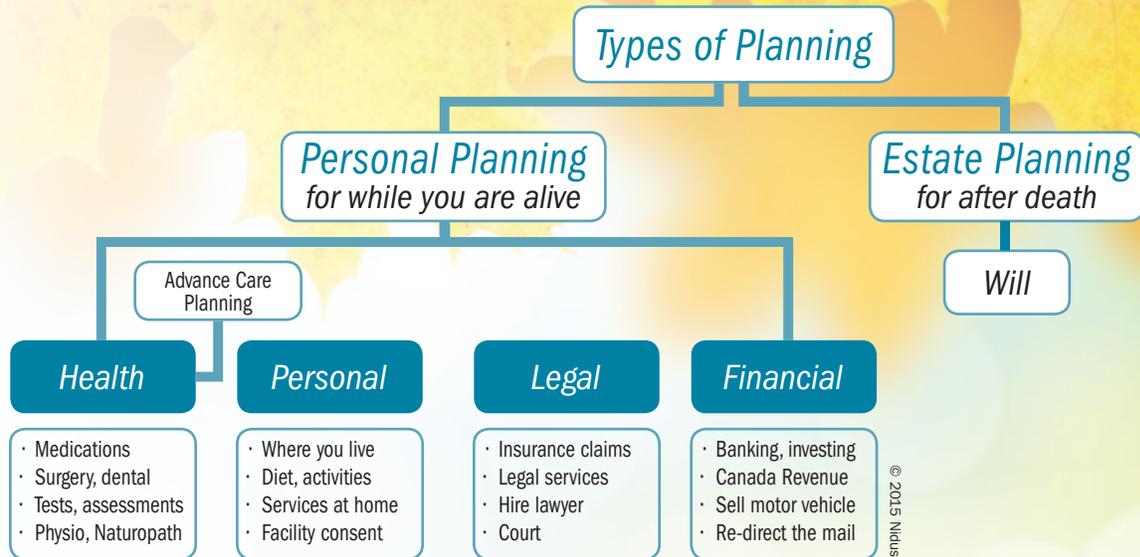
I have experienced how personal planning can improve communication within a family and quality of life for the individual. On a professional level, through Nidus, I see how personal planning has benefits for people in various types of situations, whether they are managing Parkinson's or other conditions.

? **What types of planning documents are available in British Columbia?**

There are *two paths* for personal planning in BC. The paths relate to the mental capability of the adult at the time they are making their documents. There are different documents available, depending on the path.

Most of us are on the *future path*. This means we understand the nature of what the planning documents cover and the effect of authorizing someone to help us. Like my father and I, you want to make your legal documents while you are considered capable. Nidus has information and some forms on the website – go to www.nidus.ca and

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choose the *I'm Planning on the Future Path* option. Adults on the *future path* will make two key legal documents to cover all life areas. They will make a Representation Agreement Section 9 (RA9) to cover health and personal care matters. An Enduring Power of Attorney (EPA) is the most comprehensive document for financial and legal affairs. Some adults on the future path may make a Representation Agreement Section 7 for only routine financial and legal affairs (RA7 F+L) instead of an EPA, but it does not cover as much as the EPA. Please note that an RA9 does not cover any finances and an EPA does not cover health or personal care decision making.

In BC, we have Advance Directive (AD) legislation that gives legal force to health care instructions. You must be mentally capable to make an AD. An AD has limited use on its own as it is impossible to predict the future – particularly with chronic conditions such

as PD. You must also be very careful about what you put in writing because you do not know how it will be interpreted. If you make an AD or write out any wishes in a living will, give it to your representative to apply in the circumstances you intended.

There are other options on the future path such as consent to organ or body donation. You can find information on the Nidus website at www.nidus.ca under *Information and End-of-Life Planning*.

Some adults put off their planning for too long such that they are in a position where they need assistance in their life, but their mental capability is now in question. In this case, they may not be capable to make documents on the future path. We say these adults are on the *need help today path*.

Adults on the *need help today path* may make a Representation Agreement Section 7 (RA7) as it has a different view of mental capability than the RA9 or EPA. An RA7 is a legal document. It covers minor and major health care, personal care, legal affairs and routine finances. Only BC has the RA7 for adults whose mental capability is in question. In other provinces and countries, these adults are subject to guardianship and lose their civil rights – effectively becoming a ‘non-person’. Nidus has more information and forms on the website – go to www.nidus.ca and click on the *Caring for an Older Adult Who Needs Help Now* heading.



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What steps can I take in personal planning?

1. Determine which personal planning path applies to you – the *future path* or the *need help today path*. It is important to prepare the document(s) that fit/fits your path.
2. Identify your support system. Do you have friends or family members that you trust to respect your wishes?
3. Discuss roles and duties related to your planning documents with your support system.
4. Create the relevant legal documents.
5. You may choose to register your completed documents with the Personal Planning Registry. This is a secure online service for storing your information and decisions online, while ensuring that they will become available to those who need access down the road.
6. Distribute your documents to the relevant individuals or groups – and ensure that both you and others keep them safe!
7. Review your documents and discuss your current wishes with those you named at least once a year.



Do you have any personal planning tips that may be particularly useful for people with Parkinson's?

I highly recommend using local resources available to you. My father and I are grateful to Parkinson Society British Columbia for helping us learn about the disease, resources and coping strategies. He also attended the Coquitlam Support Group. Personally, I am very excited by the Society's education on communication and swallowing as those issues were very confusing to our family at the time. Through discussions with my father, I learned more about what was important to him, which helped me in my role as his representative.

A family doctor and neurologist are also very important sources of information about Parkinson's and its expected progression, including its impact on reasoning, memory and mood. I highly recommend having in-depth conversations with your health care team about the benefits, risks and interactions of

Parkinson's medications with any other types of medications you may be taking.

My father and I gave a copy of the RA9 to his family doctor and neurologist. We would discuss any issues before an appointment, and I would make notes of symptoms to report and questions to ask. Each time, I made a copy of the notes for my father and for me or my brother. Whoever went with my father to his appointments would then be prepared to bring up issues and write down answers and advice. After the appointment we reviewed the notes and made sure to keep others in the loop. This may be a good approach for others to adopt, if it suits their needs.



QUICK TIPS:

- Do not put wording in your Representation Agreement or Enduring Power of Attorney to say that it will come into effect later. The documents may be needed at various times. They need to be in effect when signed.
- Be careful – often, although it may be helpful to include specific instructions or wishes for your family, this information is not helpful to include in the legal document itself. In this case, you can write any additional information on a separate page, which can be updated as your condition progresses.
- Have ongoing conversations – Nidus provides the *Values and Beliefs Discussion Guide* as a resource. Go to www.nidus.ca – click *Get Help*, then *Discussion Tools*.

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Hospitalization and Parkinson's disease

A trip to the hospital is rarely a welcome visit. Research has proven that people with Parkinson's are hospitalized 50% more often than their peers who do not have Parkinson's disease (PD) (National Parkinson Foundation, 2015). For people with PD, a trip to the hospital presents some extra challenges, including experiencing a worsening of symptoms, largely due to disruptions in behavior, sleep patterns, as well as medication timing. These disruptions can be further exacerbated by the lack of understanding of the disease by many allied health professionals. For example, hospital staff may not be aware that when symptoms are not properly managed, including taking medication on time, mental confusion or other side effects may occur, and in turn be mistaken for other ailments. Furthermore, some hospital pharmacies may not stock all Parkinson's medications, leading to substitutions or missed dosages. All of these factors combined may lead to an unnecessarily lengthened hospital stay. This is why it is important that patients with PD bring their Parkinson's medications to the hospital. At Parkinson Society British Columbia (PSBC), we aim to provide tools to people with Parkinson's, and their loved ones, to make a hospital stay as comfortable and stress-free as possible.

When to go to the hospital

Joseph H. Friedman of The American Parkinson Disease Association, Inc. writes that a trip to the Emergency Room is best suited for conditions such as infections, broken bones, pneumonia or surgery. He recommends against going to the hospital due to worsening Parkinson's related symptoms because it is likely that the hospital staff will not be familiar with proper treatment of the disease. Often, if an Emergency Room (ER) doctor hears about an individual experiencing a neurological symptom, they may test for a stroke – leading to a CT scan and an unnecessary hospital stay. If you are experiencing

non-threatening side effects from your medication, worsening of symptoms, including freezing or dyskinesia, it is best to consult with your neurologist or a physician who knows your history when you see changes beginning to occur (Friedman, 2007).

Medication on Time

If you do end up in the hospital, there are tools available to you through PSBC, and other like-minded organizations that can assist in alleviating complications during a hospital stay.



PSBC has a resource available called *Timing is Everything*. This is a folder available upon request, and includes a poster for nursing staff to place in your treatment file or on the bulletin board at the nurses' station. It also includes 10 post-it notes with the message: *I have Parkinson's disease. Please remember that I need my Parkinson's medication on time – every time* (Parkinson Society British Columbia, 2015).

Aware in Care Kit

This fall, PSBC will be providing British Columbians with a new resource designed for hospital stays. The Society has partnered with the National Parkinson Foundation (NPF) to bring their Aware in Care kit

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HOSPITALIZATION AND PARKINSON'S DISEASE

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to our province. The kit includes a bag that can fit Parkinson's medications, a hospital action plan, Parkinson's disease ID bracelet, medical alert card, a medication form, Parkinson's disease Fact Sheet, *I have Parkinson's* Reminder slips, as well as a magnet to help display your medication form at home or in the hospital.

Parkinson's patient, Marty Gershe, describes how the reminder slip was particularly useful when he was recently brought to the ER at his local hospital. The slip says *I have Parkinson's and I must get my meds on time, every time*. When ER staff saw this slip, they called Marty's family physician, who confirmed this necessary information, helping to ensure the successful timing of Marty's medication during his stay in the ER.

However, when he was moved to a different floor, Marty found he had to go through the process of informing the hospital staff about Parkinson's once again. He refers to pages 10–12 of the *Preparing for Parkinson's* booklet as particularly helpful. These pages emphasize the importance of being vocal, persistent and to assume everyone you meet has little to no experience with PD. When staff on the new floor didn't understand the necessity of receiving his pills on time, Marty demanded to speak with the nursing manager as well as the head of pharmacy. With help from the *Aware in Care* kit, he was able to explain to them the nature of Parkinson's and why he must stick to his existing medication schedule. He was successful in educating these staff members, and received his medications on time and every time during his visit. In Marty's words, the kit "made

me aware of what I should do, and it made a lot of health care professionals aware of what they should do for their patients" (National Parkinson Foundation, 2012).

Making your needs known

In addition to communicating the importance of medication timing, you should be prepared to advocate for yourself, as Marty did. If you experience trouble communicating, a carepartner or loved one should be prepared to help you if needed. Remember to talk to hospital staff about the following points:

- Physical and mental slowness can be associated with Parkinson's, and may be even worse at the hospital than at home.
- Communication challenges may affect your ability to use an intercom, or communicate your needs. If this is the case, you may want to bring a friend or family member with you for conversations with staff.
- Dexterity issues may affect activities such as eating, hygiene and using the intercom or other tools at the hospital.
- Lack of facial expression is a PD symptom, and may further complicate communication between yourself and hospital staff.
- Let your nurses know if you have had Deep Brain Stimulation surgery (Parkinson Society British Columbia, 2010).

Conclusion

Preparing for your stay in a hospital, as well as asking for the help of friends and family members can help alleviate your concerns. Communication with the hospital staff is key – whether you communicate via the medication on time posters, post it notes, *Aware in Care* kit, your own voice, or through a friend or family member, it is absolutely vital that the hospital staff understand the effects of the break in your routine. Even though explaining this complex disease can be difficult, you must remember that ensuring you receive the proper treatment is in everyone's best interests.



Carepartners & Bereavement

For many people, being a carepartner or caregiver is a meaningful and fulfilling experience. The carepartner experience can also be emotionally challenging as, at one point or another, a carepartner may experience grief or bereavement. Grief is a natural reaction to loss that manifests itself emotionally, spiritually or physically. Bereavement – the period of sadness that follows a death, during which grief is experienced – presents its own set of challenges.

No matter what type of grief you are experiencing, it is important not to forget about yourself,” says Courtney Hanna, Registered Clinical Counsellor and Parkinson Society British Columbia (PSBC) staff member.

Too often, people may be experiencing grief and not acknowledge it. Recognizing the emotions you are experiencing can help you cope. It is also important to understand that grief can come in waves. You may feel fine one moment and be overcome with emotion the next, but this is a natural part of the grieving process. You can choose to suppress your feelings by pushing against the waves of grief; however, this will make those waves stronger and leave you feeling weak. Alternatively, if you allow yourself to ride the waves of grief, those feelings of suffering will pass much quicker, leaving you feeling stronger and more in control of your emotions.

Types of loss

Peoples' abilities often change throughout the progression of a chronic illness. As a carepartner for someone with Parkinson's disease, you may experience different types of losses, including a loss of independence or control of the future as you had planned. With loss often comes a feeling of grief which can feel overwhelming and may be difficult to manage. Although it can seem challenging, becoming aware of your feelings rather than ignoring them will allow you to cope with them much better. The following descriptions of the various types of loss may help you understand your experience.



- **AMBIGUOUS LOSS**

One type of loss you may experience is ambiguous loss – the experience of being close to someone who is present, but who may not be “there” in the way they once were. This is typically experienced when an individual is living with dementia, brain injury or stroke. Managing ambiguous loss can be particularly challenging, especially since the individual you are caring for may have moments when their symptoms are not as prominent. In the words of Pauline Boss, Ph. D., “With ambiguous loss, there is no closure; the challenge is to learn how to live with the ambiguity” (Boss, n.d.).

- **ANTICIPATORY GRIEF**

Anticipatory grief is the sense of loss you experience long before anyone passes away – in other words, the grief you are experiencing is due to the loss of your loved one's former self. For instance, changes in speech or a diminished facial expression can make the individual you are caring for seem different. Anticipatory grief can be overwhelming and may be something you experience daily for years. While it can serve to help us emotionally prepare for the inevitable, you may experience guilt or shame for experiencing it, since your loved one is still with you.

- **BEREAVEMENT**

Recent research has shown that intense grieving can last anywhere from three months to two years or longer. After a sudden death, you may experience denial, shock, confusion and pain. It is important to remember that grief is an individual process. Some people may want to share their experience of grief, while others may isolate themselves or grieve independently.

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Grief Symptoms

Grief can manifest itself in a number of ways, taking a toll on your physical, social and emotional self. Physically, you may notice a decrease in energy, headaches and disturbed sleeping or eating patterns. Socially, you may feel detached, or want to be alone. Emotionally, you may feel everything from intense sadness, to irritability or even euphoria.

Effects of Bereavement

During the bereavement process, you will likely experience many symptoms similar to grief. However, due to the specific complexities of losing a loved one, you may experience additional effects. You may become worried about your own physical health, and develop symptoms similar to those of your loved one. You may experience intense anger – this includes anger at your loved one or the medical system. Some people face spiritual challenges related to the loss and a perceived lack of life's meaning. These are all seemingly logical effects of losing a loved one. However, you may also experience some emotions and thoughts that surprise you. The following is a brief list of bereavement effects that are quite common:

- Believing that you can see, hear or feel the deceased
- Inability to remember your loved one
- A preoccupation with thoughts of your loved one
- Treasuring your loved one's belongings, or objects that represent your relationship with them
- Vivid dreams about your loved one
(Recover-from-grief.com, n.d.)

Bereavement is a challenging process that may be overwhelming at times. You can take some comfort in knowing that it is experienced by many, and although the feelings and symptoms may be disturbing, it is possible to emerge with a full life and stable emotional health. "It is important to remember that there is no right way to grieve," says Courtney, "being patient and compassionate with yourself can provide you with the space and time you need to deal with these emotions."

You are not alone

Some people may look inwards during the grief or bereavement process – journaling, meditation and self-reflection may be helpful ways for you to manage your grief. However, it may also be helpful to look for external supports. At PSBC, we noticed a trend; carepartners became a part of the Parkinson's community while a loved one was ill, but felt socially isolated when the loved one passed. This is part of why we – alongside our partners at Pacific Parkinson's Research Centre – established the bereavement support group for anyone affected by Parkinson's disease who has recently lost a loved one. In addition to this group, there are dozens of support groups for care partners across the province.



Finally, PSBC's free counselling services may be of interest to individuals affected by Parkinson's. Courtney Hanna (RCC) and Myriame Lépine Lyons (CCC) are both qualified counsellors available to offer support in person, via video chat or telephone to residents of British Columbia or Yukon. Regardless of how you manage the bereavement process, remember – you are not alone.

For information on PSBC's counselling services, please visit our website:
<http://www.parkinson.bc.ca/counselling>

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JOANNE TAYLOR ANSWERS YOUR QUESTIONS ON PERSONAL PLANNING

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What is Nidus? Who is behind it?

Nidus (Latin for nest: a symbol of support and safety) was established in 1995 by citizens and community groups to be a resource on Representation Agreements and personal planning. It is a leader and trusted resource on personal planning in BC and internationally. We collaborate with health care and legal professionals, and with government, but we are independent. As a non-profit charity our mandate is to serve the public.

Nidus grew out of a grass-roots legal reform to create health care consent legislation, as well as the Representation Agreement Act (RA Act) to provide new planning tools. The RA Act gives British

Columbians a legal way to plan for health and personal care matters. It also offers a legal alternative to adult guardianship.

The idea of a centralized registry for personal planning documents came out of the law reform. It is something the public wanted. The BC government decided not to set up a registry service, but they encourage the public to use the Nidus Personal Planning Registry.

You will find lots of information, Representation Agreement forms and access to the Registry at the Nidus website www.nidus.ca. Nidus provides personal help by appointment and you can book online at the website – select *book now* in the right sidebar.

HOSPITALIZATION AND PARKINSON'S DISEASE

continued from page 10...

Our office and website have more resources available on hospitalization and Parkinson's. For more information about the Aware in Care kits, please contact Stacey Dawes, Information & Programs Manager at 1 800 668 3330 or sdawes@parkinson.bc.ca.

References:

Friedman, Joseph H. (2007). *Educational Supplement #16 When Should Parkinson's Disease Patients Go To The Emergency Room?* Retrieved August 17, 2016, from http://www.apdaparkinson.org/userfiles/files/16sup_Rev2007.pdf

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Parkinson Society British Columbia. (2015). *PD Medication: Timing is Everything*. Retrieved August 10, 2016, from <http://www.parkinson.bc.ca/media/34294/tie-2.jpg>

National Parkinson Foundation. (2012). *Aware in Care: Real Stories*. Retrieved August 19, 2016, from <https://www.youtube.com/watch?v=ZY0J4xAEw5w>

National Parkinson Foundation. (2016). *Aware in Care Kit*. Retrieved August 17, 2016, from <http://www.parkinson.org/find-help/aware-in-care-kit>

West Coast College of Massage Therapy

West Coast College of Massage Therapy holds a special massage clinic for people with Parkinson's, caregivers and support workers.



The clinic is on **Thursdays from 4:00 pm to 7:45 pm**. The cost is \$13 for people with Parkinson's and \$22 for carepartners and support workers.

We have received excellent feedback from those who have attended the clinic. If you are interested, please call the clinic receptionist at **604 520 1830**.

Access is through the back entrance on Clarkson Street and is wheelchair accessible.

613 Columbia Street
New Westminster, BC

(Near 6th Street, one block from
Columbia Skytrain Station)



West Coast College of MASSAGE Therapy

World Parkinson Congress

World Parkinson Congress 2016

On September 20th–23rd, 2016, the triennial World Parkinson Congress took place in Portland, Oregon. Bringing together over 4,400 physicians, neuroscientists, health professionals, carepartners and people with Parkinson’s disease (PD), from over 60 countries, the Congress offered a unique and inspiring experience. Five members of the Parkinson Society British Columbia staff, as well as over 40 individuals from BC who received travel grants through the Society, were in attendance. They had the opportunity to learn about the latest scientific discoveries, medical practices, caregiver initiatives and advocacy work related to Parkinson’s disease. It is our hope that the knowledge gained from the Congress will help shape the Society’s future programs and services, ensuring best treatment practices for those affected by PD.

PSBC’s Abstracts on Display at WPC



WPC 2016 accepted poster abstracts from both health professionals engaged in research, as well as from the community of people living with PD, who are involved in activities and programs creating change for the PD community. We are pleased to share that three abstracts submitted by PSBC were selected for presentation at the Congress, including

Advocacy is Education: Developing Support for a Provincial Parkinson’s Strategy in British Columbia, Communication & Swallow Workshop and This is Parkinson’s Disease. Two of these abstracts were also identified to be in the top 10% of all submissions and invited to be a part of the Congress’ Poster Tours. We encourage you to review the abstracts chosen for presentation by visiting: <http://www.parkinson.bc.ca/resources-services/resources/#WPC>.



Caroline Wiggins, Education & Support Services Coordinator (left) and Stacey Dawes, Information & Programs Manager (right) greeting attendees at Parkinson Society British Columbia’s exhibition booth in the exhibit hall.

Highlights by Topic

Stem Cell Research

Recent studies on stem cell therapies to treat Parkinson’s disease have yielded differing, and even conflicting, results largely due to the range of patients used, as well as the varying “doses” of cells, delivery approaches and follow-up executed.

Attempts are being made to remedy this through a new TRANSEURO trial (<http://www.transeuro.org.uk/>). Furthermore, “a global consortium that brings together the major funded teams working on developing a stem cell-derived neural transplantation therapy for Parkinson’s disease (PD)” has been set-up (Barker, Studer, Cattaneo, Takahashi & G-Force PD consortium, 2015). This consortium, G-Force PD, involves teams from Europe, USA and Japan. View the slides related to this presentation at:

<http://bit.ly/WPC2016-BarkerPPT>.

continued on next page...

Interested in participating in stem cell research?

Presenters at the World Parkinson Congress warn patients and their loved ones to be wary of any trials that require payment for participation. The International Society for Stem Cell Research (ISSCR) has developed the ISSCR Patient Handbook on Stem Cell Therapies. This publication was created with information to help patients and their families evaluate stem cell treatments they may be considering. It is available online at: <http://www.isscr.org/home/publications/patient-handbook>.

Levodopa Induced Dyskinesia

Dyskinesia is best described as an abnormality or impairment of voluntary movement. Levodopa-induced dyskinesia is the impairment of voluntary movement caused by Levodopa medication. While Levodopa is often deemed the most effective pharmaceutical therapy for people with Parkinson's, dosing and responsiveness, disease severity and duration, and age of onset are considered cardinal factors to developing dyskinesias in the long-term.

Some research findings suggest that dyskinesia interferes with daily activities, increases clumsiness in activities that require precision, causes weight loss, postural instability, fatigue and pain. While findings are still contradictory, there is no doubt that dyskinesia can negatively impact the quality of life on an individual basis. Levodopa-induced dyskinesias may be intrinsic to the use of Levodopa.

Research is finding new ways to predict and treat dyskinesia. Currently, to control dyskinesias, improved dopaminergic therapies (especially improved Levodopa delivery) may lessen their expression. For more information about managing levodopa-induced dyskinesia by improved drug delivery, view Dr. Peter A LeWitt's slides here: <http://bit.ly/WPC2016-LeWittPPT>.

DID YOU KNOW

1. The difference between chronic care and palliative care is that the former regards preserving function and prolonging life, while the latter regards relieving suffering, planning for end of life, and focusing on the patient and family for the seriously ill.
2. If integrating cannabis into your treatment plan, it is recommended to return to the same dispensary and try the same or different types of formulations, rather than jumping from various dispensaries and trying different formulations.
3. If chosen to receive Deep Brain Stimulation (DBS) therapy, it is best to work with an interdisciplinary team (i.e., neurosurgeon, neurologists, therapist, nurses) to set realistic expectations of the surgery outcome. This helps enhance benefits.
4. Fatigue, a non-motor symptom associated with Parkinson's, is very common. Between 33–70% of people with Parkinson's will report issues with fatigue.



Help us win funding for our Aware in Care Kits!

VOTE FOR PSBC's project by visiting this link:

<https://www.avivacommunityfund.org/voting/project/view/16-336>

Are you interested in the Aware in Care kits described under the "Living AWell" section of this issue of *Viewpoints*? Parkinson Society British Columbia (PSBC) has submitted a project proposal to the Aviva Community Fund to help with the cost of offering Aware in Care kits to BC's Parkinson's community. This year, Aviva will be providing a total of \$1 million to the Grand Prize Winners.

You can help by casting your votes for us! Each person who registers through the website can cast 18 votes at any time during the voting round. You can even cast all of your 18 votes for one project! The 15 ideas that receive the most votes between October 11th and 28th, will become finalists. On December 6, a panel of independent judges will select the Grand Prize Winners.



Thank you to everyone who participated in, and donated to, this year's Parkinson SuperWalk! We are pleased to share we have raised \$399,519 to date!

Don't forget that you can still make donations to SuperWalk until December 30th online at www.superwalkbc.kintera.org, or by cheque.

SPONSOR



New!

YOPD & Young at Heart Support Group in Langley

If you've been diagnosed with Parkinson's, this new support group in Langley may be for you! The group aims to bring together those with Young Onset Parkinson's Disease (YOPD), their carepartners and any member of the PD community who considers themselves young at heart. Members will support each other in their life and/or fitness goals, whether that means lending an understanding ear, or cheering one another on at the finish line! Although this group will encourage an active lifestyle, it is not a requirement, and all are welcome.

Dates: 3rd Sunday of each month
Time: 10:00am – 12:00pm
Place: Willoughby Community Centre at Langley Events Centre

▶ For more information, please visit: <http://www.parkinson.bc.ca/resources-services/support-groups/>

New!

YOPD Online Support Group Pilot

Parkinson Society British Columbia is piloting an online support group facilitated by Myriame Lépine Lyons. A valid internet connection will be required to participate.

Dates: 2nd Tuesday of each month, beginning October 11, 2016

Time: 7:00pm – 8:00pm

▶ You must register to attend this support group by contacting Myriame Lépine Lyons at mlepinelyons@parkinson.bc.ca or 1 800 668 3330



Corporate Gifts & Fundraising Events

9th Annual Me-n-Ed's Charity Golf Tournament & Raffle

Parkinson Society British Columbia received \$5,000 from the Me-n-Ed's Charity Golf Tournament. Additionally, raffle ticket sales totalled \$4,970! Thank you Me-N-Ed's!

First Annual Sparwood Golf Tournament

A big thank you to Merl Shelley and the Sparwood community for coming together and making this event, in memory of Joe Tracey, a roaring success! The total raised at this event exceeded their \$2,500 goal for a total of \$5,260. Looking forward to next year and beyond!

Move to Improve Photoshoot Fundraiser

Sisters Heidi and Robyn from ZHOOSH Fitness Garage combined photography and fun to help raise \$831 for PSBC. Thank you for your support!

Brian and Spencer Rasmussen's Paddle for Parkinson's

A huge round of applause to Brian and his son Spencer for their massive efforts in paddling 700km (in not such a sunny June) to raise a very hard earned \$15,784!

PSBC Fall Online Auction

Our 2016 Fall Online Auction launches on Wednesday, October 19. Bid on an array of items and experiences that include travel, wine and sporting events. 100% of the proceeds benefit Parkinson Society British Columbia. Visit <http://www.parkinson.bc.ca/how-to-help/fall-online-auction/> or look for details on social media in the coming weeks.

Tony Burrows' 60th Birthday

On his 60th birthday, Tony decided to give back with a big present to PSBC. Thank you to Tony, and his generous family and friends for their donations that totalled \$1,825.

Pull for Parkinson's

Thank you to Mariam Hanjra, Thomas Canale and all the high school ultimate frisbee teams that came out again this year for their annual tournament, raising a high flying \$3,014!

KPMG Kamloops Jeans Day with Teri Denis

We are grateful to have the support of Teri and her colleagues whose jeans day helped raise \$554 for PSBC. Who knew raising money could be so cool?

A&W Float Sales with the Vancouver Canadians

Many thanks to the fantastic staff at A&W's Newton/Strawberry Hill locations. Float sales at the baseball games helped raise \$2980.50!

Thank you to **Team TELUS Employee Charitable Giving Program** for their generous donation of \$10,490.64 this August!



October

DEBRIEFING THE CAREGIVER ROLE – GROUP SESSION

27 Vancouver

Date: Thursday, October 27, 2016

Time: 1:30pm–4pm

Place: Oakridge Branch
Vancouver Public Library
191 – 650 West 41st Avenue, Vancouver

Cost: Free

REGIONAL CONFERENCE

29 Kamloops

Date: Saturday, October 29, 2016

Time: 10am–4pm

Place: Thompson Rivers University
Mountain Room
900 McGill Rd, Kamloops

Cost: \$30 Member
\$50 Member (Couple)
\$40 Non-member
\$70 Member (Couple)

November

CAREPARTNER CONNECT

3 Webinar



Providing emotional and educational support, Carepartner Connect is a 4-week webinar series for carepartners of people with Parkinson's. Topics include: caregiver wellness, regaining autonomy, cultivating intimacy, managing changes and transitions, and much more.

Date: Thursdays for 4 weeks beginning November 3rd, 2016

Time: 11am–12:30pm

Place: via webinar
Instructions on how to login and access these presentations on a computer with Internet access will be provided closer to the event date.

Capacity: 95

Cost: Free

FOOD FOR THOUGHT: DIET & NUTRITION IN PD

4 Two Community Talks

Dr. Laurie Mishley, ND, MPH, PhD, will be sharing her research and knowledge about nutrition in Parkinson's disease at two community talks.

Abbotsford Community Talk

Date: Friday, November 4, 2016

Time: 9:30am–11am

Place: Quality Hotel & Conference Centre
Pinnacle Room 2
36035 North Parallel Road, Abbotsford

Cost: Free



2017

Burnaby Community Talk

Time: 2:30pm–4pm
Place: Executive Hotel & Conference
Centre Burnaby
Centennial Room
4201 Lougheed Hwy, Burnaby
Cost: Free

REGIONAL CONFERENCE

5

Victoria

Date: Saturday, November 5, 2016
Time: 10am–4pm
Place: Sandman Hotel Victoria
Orchid Room
2852 Douglas Street, Victoria
Cost: \$30 Member
\$50 Member (Couple)
\$40 Non-member
\$70 Member (Couple)

ROADSAFETYBC WEBINAR

22

 Webinar

Catherine Douglas and Kevin Murray from RoadSafetyBC will join Parkinson Society British Columbia for an engaging presentation about driving with Parkinson's disease.

Date: Tuesday, November 22, 2016
Time: 11am–12pm
Place: via Webinar
Cost: Free

SHAKE, SHAKE, SHAKE CONCERT

January 27 – Vancouver

Emily Chambers is back with musical guests for an evening of entertainment in the heart of Vancouver.

Date: Friday, January 27, 2017

Place: The Imperial
319 Main Street, Vancouver

Cost: \$25 Regular
\$125 VIP reception & concert

(\$65 tax receipt. Receipts will be issued in 2017 following the event.)

 To purchase tickets, visit www.parkinson.bc.ca/how-to-help/shake-concert

COTSWOLDS WALKING HOLIDAY

Aug 31–Sept 8 – England

Join experienced long distance walker, Brian Wood, on the Cotswolds Walking Holiday benefitting Parkinson Society British Columbia.

Date: August 31 to September 8, 2017

Place: Bourton-on-the-Water, England

Cost: Land packages \$1,969.00;
Air & land \$3,269.00

Please note that participants will be responsible for their own travel arrangements and costs. All donations accumulated through fundraising will help provide essential programs and services to people with Parkinson's through PSBC.

STEP 1 – Make your travel arrangements with Peter Wheaton at Athlone Travel.

 Phone: 250-598-5252 | Toll Free: 1-888-987-2351
Email: peter@athlonetravel.com

STEP 2 – Register online to fundraise for PSBC on the Cotswolds Walking Holiday.

 Visit <http://pdchampions.kintera.org/cotswoldswalk>



Stay connected to the Parkinson's community!

Get an annual membership for you & your household for only

\$25

Renew your membership with Parkinson Society British Columbia and continue to be a part of our friendly, caring and supportive community.

For only \$25, you will receive an annual membership for you and your household valid until December 31, 2017.

Reasons to renew your membership:

- **Enjoy discounts.** In 2016, we delivered important educational events to even more cities in British Columbia. Whether you join us for a Regional Conference or workshop, your membership provides you with great discounts on important events!
- **Stay informed.** Get the latest information on research, medication, caregiving, exercise, wellbeing and nutrition when you receive *Viewpoints*, our quarterly newsletter.
- **Be heard.** Vote at our Annual General Meeting and add your voice to the community to garner support from donors, sponsors and politicians.
- **Gain support.** Be a part of our provincial network of more than 50 support groups and/or speak with our knowledgeable and compassionate staff.

▶ Visit www.parkinson.bc.ca or return the insert inside this issue of *Viewpoints*.

▶ Questions? Call or email Susan Atkinson, Donor and Member Services Coordinator
604 662 3240 | 1 800 668 3330 | satkinson@parkinson.bc.ca



600—890 West Pender Street
Vancouver, BC V6C 1J9



RETURN POSTAGE GUARANTEED
PORT DE RETOUR GARANTI